Information Leaflet

NHS
Liverpool Women's
NHS Foundation Trust

Care After Cancer of the Ovary

Introduction

You have now completed treatment for cancer of the ovary. This leaflet has been written to support you moving forward; with guidance on recovery, getting back to "normal", follow up and to help you decide if, or when you should contact your Gynaecology Oncology Clinical Nurse Specialist (CNS). Your CNS and cancer support worker will be happy to provide further information and advice on all aspects mentioned in this leaflet.

Recovering from cancer treatment

After treatment you will probably be keen to get back to a sense of ordinary life. However, you may still be coping with the side effects of treatment and with some difficult emotions. You may find you have 'up' and 'down' days for a while afterwards. Recovery takes time, so try not to be hard on yourself.

Recovering from surgical treatment for ovarian cancer

There is very good evidence that by encouraging patients to return to normal as quickly as possible following surgery, reduces problems and complications. This is called an enhanced recovery and you will have received information about this during your hospital admission. Your recovery will depend on many things which makes it difficult to give an exact timeline. We encourage you to try to do a little more each day and use self-awareness to determine what is right for you. Another factor in your recovery is the type of surgery you had. If you had keyhole (laparoscopic) surgery your recovery should be quicker, and most women are able to do most things after a few weeks. If you had a traditional, larger incision (laparotomy) recovery can be a little longer. Usually this can take several months for you to feel fully recovered. Information regarding your recovery will have been provided to you prior to your discharge from hospital. However, if you do have any questions, you can contact your CNS and cancer support worker.

Depending on your diagnosis, further treatment may be required, this being adjuvant (additional) chemotherapy. Not everyone needs adjuvant (additional) treatment after surgery, and this will be considered by your oncology team. Adjuvant chemotherapy would start approximately six weeks after your surgery. This allows time for recovery after your surgery.

Chemotherapy

Not all women will have or require chemotherapy for the treatment of their ovarian cancer; this is decided based on your ovarian cancer diagnosis.
Chemotherapy can be given after surgery, known as adjuvant (additional) chemotherapy or in some cases, is given before and after surgery, known as neoadjuvant chemotherapy. This section applies to you if you have had, or you are going on to have chemotherapy. Additional information and advice will be provided by your medical oncologist and CNS team.

There is a risk of recurrence with certain types of ovarian cancers, and we would strongly advise you to be aware of any new changes or symptoms. If you notice new symptoms or have any problems between appointments, contact your CNS team for advice.

Sometimes CA125 blood tests are done as part of your follow-up but this is not always needed. A rising CA125 level may be a sign that the cancer has returned and will help us to consider further tests such as a CT scan to investigate this further and assess whether further treatment should be considered.

The impact of ovarian cancer

Being diagnosed with ovarian cancer, being treated for ovarian cancer and reaching the end of treatment for ovarian cancer can have both an emotional and physical impact on you. For some it is a sign that things can start to get back to “normal”. Many women return to a state of normality or can find and be comfortable with a new normal, yet for others, this may be more difficult. There is no right or wrong way to feel. Your CNS will be happy to provide more information on all the areas mentioned below.

Emotional Impact

Coping with an ovarian cancer diagnosis and treatment can be hard. You may have many different emotions, from numbness, shock, or fear, to anger, guilt, or sadness. It may leave you feeling out of control of your life and future. It is often more difficult to deal with the unknown, so having the right amount of information and support may help you feel more in control. Your CNS is happy for you to talk through any concerns or questions when you have them. After treatment, you may feel relieved that it’s over but also nervous about the future. It is common to feel anxious that the cancer may come back. Knowing the risks and what options are available if this happens can help you to cope with any fears.

Physical Impact

Fatigue: Though fatigue is a common symptom after surgery, radiotherapy and chemotherapy, there are steps you can take to reduce and cope with this. Top tips include – take it easy, conserve your energy, maintain your energy & get moving.

Diet: Evidence shows that maintaining a healthy weight, avoiding excessive weight gain, and maintaining levels of physical activity is associated with an improved quality of life and enhanced recovery. Top tips: keep to your meal routines, chose reduced fat, walk off the weight, pack a healthy snack, look at labels, caution with your portions, think about your drinks & focus on your food.

Scaring: Depending on the type of surgery you have; you may have some scars. These should fade over time. Some scars may cause localised numbness which should improve after a few months. If you have any problems with scaring speak to your surgical team and CNS.

Changes to your bowel or bladder: After surgery and treatment, some people experience changes in how their bowels, bladder or both work. Sometimes these changes only last for a short period of time and eventually improve. However, for some people, these changes can be more persistent, may get worse after treatment or may only develop a while after treatment has finished, known as a late effect from treatment. If you experience bowel or bladder changes, it is important to speak to your CNS who can help you get the right support.

Menopause: Most women who experience ovarian cancer will have already gone through menopause. However, some post-menopausal women may re-experience their menopausal symptoms and/or develop new symptoms following surgery to remove their ovaries. Menopausal symptoms can also return following chemotherapy. Women who were pre-menopausal prior to diagnosis and have surgery for their ovarian cancer, may develop symptoms of surgically induced menopause following the removal of their ovaries. Hot flushes and night sweats are the most common menopausal symptoms. Many women also notice weight changes, sleep disturbances, vaginal dryness and changes in libido. If you are suffering from vaginal dryness, vaginal lubricants and moisturisers can be prescribed.

Most women with ovarian cancer can safely take Hormone Replacement Therapy (HRT) for the management of menopausal symptom and there are many different forms of HRT available such as tablets, patches and creams. HRT, however, may not be suitable for all women with ovarian cancer so you should discuss taking HRT with your medical team or a menopause specialist. Alternatively, some women find changes to lifestyle, herbal remedies and complimentary therapies such as acupuncture, hypnotherapy, massage, and aromatherapy helpful for their symptoms. Do tell your CNS or GP if menopausal symptoms are troubling you.

Resuming sexual activity: It is not uncommon to lose interest in sex and intimacy following your treatment for cancer. Cancer and its treatment can cause physical and emotional changes that may affect your sex life. You may also have changes such as scars or hair loss that affect your body image. It is strongly advised that you abstain from penetrative intercourse for 12 weeks following your surgery as stated on all other leaflets We strongly encourage you to share your feelings with your partner if your feelings towards sex and intimacy have altered and take time to introduce intimacy if you wish to do so. If you feel you have ongoing problems with sex and intimacy that are not getting better with time, you may wish to consider speaking to a psychosexual counsellor.

Other concerns

Support: Some people prefer not to talk things through, while others get support from speaking about their experience. Details of support groups can be provided by your CNS. Exercise: Try to gradually increase your daily activity, with the aim of trying to build up to four or more thirty-minute sessions each week of activities that increase your heart rate. If you require further information to access any local programmes, please speak to your CNS team.

Work: You can return to work whenever you feel ready to do so. All jobs are different, so it is hard to be specific. Whenever you return to work, remember it may be a shock to the system to begin with and it can be very useful to return in a phased manner, increasing your work hours over a few weeks.

Financial concern: You will be eligible for free prescriptions, if you are not in receipt of this please speak to your CNS. You may also be entitled to certain grants and benefits; this can be individually assessed, or you can call the Macmillan helpline on 0808 808 00 00. If any other financial issues are causing you worry, speak to your CNS who can offer advice on who can help.

Travelling abroad: Once you have completed your treatment, there is no reason not to travel abroad. Sometimes patients can have trouble in acquiring travel insurance. Your local Macmillan Support and Information Centre and the Macmillan website will be able to offer advice.

Follow up

Clinical follow up. Once you have completed your treatment, you will begin a five-year surveillance period . The aim of this is to ensure everything is going well post treatment and to explore any of your concerns. You will have traditional follow up appointments every 3-6 months which may be face to face, video consultations, telephone appointments or patient supported follow up. During your appointments you will be asked questions about your recovery and any side effects or symptoms you have been experiencing. You may also be offered a pelvic examination and a CA125 blood test. If you are experiencing problems or are worried about anything between your appointments, you are encouraged to contact your CNS team who can assess you and if needed, can bring you back in for a clinic appointment sooner.

When to contact your CNS

It is important to remember you will still get coughs, colds, aches and pains and bowel upsets just like anyone else. Your GP will normally be happy to treat such problems. However, if they are concerned about your symptoms when they see you, they can contact your CNS who can arrange a clinic appointment.

We would like you to contact your CNS if you have any of the following symptoms and they persist for more than two weeks:

- Pain in the stomach or pelvis that was not present previously.
- Persistent bloating or swelling of the stomach.
- Bowel changes, if this is new e.g., diarrhoea or constipation.
- Bleeding from the vagina
- Bleeding from the back passage
- New aches and pains or lumps in abdomen
- Weight loss without dieting or exercise.
- Feeling generally unwell.
- Swelling of the legs.

It is important to remember that even if you have some or all these symptoms it does not necessarily mean the cancer has come back but we will arrange to see you in clinic to check you over. Do remember, however, that some of these symptoms can also be caused by other conditions that are completely unrelated to ovarian cancer. So please do not become unduly anxious while awaiting your review.

You can contact your CNS team Monday – Friday 8am – 4pm using the details provided at the end of this leaflet. If you phone and they do not answer, please leave a message and contact number on the answer phone, and you will be contacted as soon as the CNS picks up your message.

Worries about cancer returning

It is entirely natural to feel anxious that your cancer may return, and we recognise that this can make you feel very uncertain about the future and lead to difficulties in “getting on with life”. Should there be any cause for concern you will be reviewed by the clinical team. Appointments and appropriate investigations will be organised for you.
Ways to manage worry and uncertainty about cancer

- Learn to focus on the ways cancer has made you a stronger person.
- Talk to family and friends about your concerns
- Join a support group
- Write a diary about your fears and feelings.
- Get involved with an interesting hobby or other things you enjoy doing.
- Review your priorities towards interesting and meaningful activities.
- Remember that as time goes by, your worries can fade.
- If depression, anxiety or any part of the cancer journey becomes overwhelming seek advice from your CNS or GP

How to contact the Gynaecology Oncology Clinical Nurse Specialist team:

Monday to Friday 8am-4pm telephone **0151 702 4186**.

If you get the answerphone please leave your name, date of birth, telephone number and a brief message. Your call will be answered within 24 hours, or on the next working day if it is a weekend or bank holiday.

Support Networks Available Locally

Further information, advice and support are available for yourself/partner and family from:

Lyndale Cancer Support Centre - Knowsley
Tel: 0151 489 3538

Sefton Cancer Support Group
Tel: 01704 879352
www.seftoncancersupport.org.uk

St Helens Cancer Support Group
Tel: 01744 21831

Warrington & District Cancer Self-Help Group
Tel: 01925 453139

Widnes & Runcorn Cancer Support Group
Tel: 0151 423 5730

Isle of Man
Manx Cancer Help Association
Tel: 01624 679554
www.manxcancerhelp.org

Liverpool Sunflowers
Liverpool Cancer Support
Tel: 0151 726 8934

The Wirral Holistic Care Services
Tel: 0151 652 9313
www.wirralholistic.org.uk

Maggie’s Centre Clatterbridge
0151 334 4301

OVACOME
www.ovacome.org.uk

The daisy network
www.daisynetwork.org.uk

Menopause Matters
www.menopausematters.co.uk

Macmillan
Tel: 0808 808 0000
www.macmillan.org.uk

This leaflet can be made available in different formats on request. If you would like to make any suggestions or comments about the content of this leaflet, then please contact the Patient Experience Team on 0151 702 4353 or by email at pals@lwh.nhs.uk

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Tel: 0151 708 9988
Issue Date: Feb 2023
Reference: Mac_2023-138-v2
Review Date: 28/02/2026